NAMI CALIFORNIA STATEWIDE MHSA ADVISORY POOL
RESPONSES TO QUESTIONS ABOUT
THE MHSA STAKEHOLDER PROCESS
11-13-07

Copied for the OAC

Email sent October 22, 2007
(Responses copied and pasted as written. Not a "statistical analysis" but certainly gives us the human voice.)

Dear NAMI MHSA Advisory Pool:
In the next couple of weeks, I'll be meeting with the Department of Mental Health to give them our feedback on the MHSA Stakeholder process. It would be helpful to know your thoughts so that I might include them in the report to DMH.

Please send me your opinions/reflections and briefly answer any or all of the following:

How is the MHSA stakeholder process working in your county? What is good/not-so-good/or could be improved?

1. I don't do so good on the computer and I have lots to say about the mhsa or prop 63. I have been involved with this county's "transformation" since the start of this. I facilitated focus groups of my peers aka "consumers" I drove to Riverside countless times to participate on stakeholder leadership committees and the only change I see is in myself. What good I thought I was doing at the time has now turned out to be a NIGHTMARE. WE Peers are not providing consumer driven services. Hardly any have been hired-- some have been fired and all the while we and our families suffer..... endlessly it seems. How much more

patience is required of us? My family wants me to do nothing more because it costs us too much. As long as things stay this way we are stuck in hell. What can Nami or anyone else do to really change this system??? I personally give up . Thank you for doing what I cannot.

2. Often don't find our put about meetings until it is to late to plan to attend. These meetings are often to far away and coordination in our area is required in order to get anyone to any such meetings for our voices to be heard.

3. In a word, fair. A Consumer and Family Advisory Committee was formed but has done little "advising" so far even though it has been in existence for more than a year. Reasons are:

   a. Meetings are held in a remote area of the county midway between the two largest population centers and are held in mid afternoon on weekdays which means that anyone who has a regular job is pretty much excluded from participation. This has seriously skewed and limitied the population of consumers and family members who attend.

   b. Much of the time in most of the initial year's meetings have been around process, not issues relating to implementation of the act. This situation is improving over the past few months.

   c. Until very recently when Advisory Committee members voiced concern, none of the nine CSS programs being implemented in our county has made use of the Advisory Committee to provide insight or advice from the consumer or family perspective.

4. The stakeholder process allows for divergent views. But it is dominated by providers or other actors who can afford to send a full time employee. That means the consumers that go are paid employees who represent, in some respects, the views of the people they work for. The same is said for the providers. NAMI members are often retirees who go to meetings but do little to particpate.

   The other thing is that stakeholder process, while allowing an open exchange of views, is not as influential as hoped. The board of supervisors routinely changes things around. The stakeholders make decrees also how money should be spent, then DMH changes what those guidelines are without informing the stakeholders.

5. Been so out of the loop w/everything going on here. Finally contained my Son and am working to get him conserved (again) and, hopefully, into La Casa--an excellent long-term facility for D.Dx'd which is located in Paramount (within a 10 min. drive from my trailer).
   I can tell you that there are a lot of artificial roadblocks being set up surrounding FSP's. In our case, SouthBay MH did not follow thru w/their initial eval and never actually got Jeff enrolled as he went into a Hospital in different Service Area. Starting all over in Glendale Memorial's area became problematic when he moved into Portal's housing. In fact, the ACT program manager at Portals was also handling the FSP program and kept

telling Jeff when he would go over to their office daily that he was not on the program. Even tho Nancy Weiner (who is one of the top administrators of the FSP Program for the whole Co.) told the Manager repeatedly that she herself had processed Jeff's app, and I know the Manager even visited Nancy at DMH, all the months he was staying at Ramparts--Portal's housing--trying to get hooked up w/their Clubhouse (which entailed yet another FSP program) never resulted in their acknowledging his status as an FSP client!

Even more frustrating, when Jeff had to be hospitalized again in a hospital in OC (where he still is), when we approached Exodus Program (yet another FSP program) to become his casemanager, in order to close his FSP in Portal's SA, they were told Jeff was in Portal's ACT Program. And now, I'm told by my Service Area 8 Representative that one cannot get an FSP if one is currently an ACT client!!

If you can follow that....I just hope he gets into La Casa, because we've given up FSP's!

6. Unfortunately I do not attend these meetings because I work so I am afraid I have no constructive output on this. And that would be my input on the system. Family members who work are left out of the process because the meetings are structured to be convenient for those who work in the system. so you get a lot of consumer representation but little on the family side.

7. I only went to one meeting (with my daughter and her friend, both 18 with bipolar). We were all so disillusioned we did not return. The purpose seemed for DMH to gather foster children and have them speak their needs. I certainly understand this, but the meeting was lobbied so heavily by DMH members that as a family member (there were only 2 NAMI members out of 150 people) I felt very overwhelmed

8. **The meetings include a VERY broad cross-section of our county including an increasing number of Hispanic representatives from local El Concillio, et. I would like to see more consumer & family members included, although there are people with children's issues that may be representing more family members than I realize.**

9. I have some concerns. So far meetings have not been held at a time when family members can attend. We have expressed this concern and are hoping for a change. Consumers attend in an abundance, but we have had few family members. At both county and state meetings although time limits are given for people wishing to speak, they are not enforced resulting in the same people speaking many times and repeating themselves.
   I would like to see meetings planned far enough ahead and at night to afford an opportunity to recruit more family voices.

10. OC's MHS Dept. needs to have Stakeholders meetings in several locations during each year for the community to have better access.

11. In Shasta County the stakeholder process stopped with the initial focus groups. The initial "stakeholders" were determined to be community organizations/agencies/non-profits. There was very little effort to ask the REAL community of consumers/youth/family/interested friends

what the needs/barriers/wants were. Community meetings that were advertized would have been better! Town hall type meetings.

The two-tier system is very evident in our county. When we asked for help in getting assistance for our ill homeless friends and relatives, we did *not* mean to ignore individuals who knew how to access the building/services. People go in and out of their illnesses, and may stop taking medications and become dangerously ill. When a person is in this state, we should not say that they have been *recently* "engaged with services" and therefore ineligible for intensive outreach and re-engagement. The individuals who need this level of care should be a full service partner and receive more help when needed, and less when they are better. By having a "**special team**" for full service partners, rather than integrating into the system, people are excluded.....or just put on an outreach list to be contacted when there is time. If there were truly an outreach team who went into the community and contacted individuals, we could save lives (this team should be required to have a client as a paid staff member and a family member also). By having outreach and FSP personal service coordinators doing the same job, when will there be time for real outreach? Can we ask what responsibility the County has for individuals who have been referred to a FSP team and are on the Outreach List? Sometimes when *liability* is a concern, people are more aware of their *responsibilities* for the safety of people.

We need to look at the needs of individuals in our system, and the need may change from day to day. The "special" full service partnership team leads to the two-tiered system. If the individuals were integrated into the regular teams of Psychiatrist, Clinician, Nurse,Psychologist, Personal Service Coordinators, Consumer Advocate and Family Advocate.....their needs could be better addressed along with other team clients. If we lose our teams....we are going back in time ten to twenty years.

If Counties are thinking that they will save money by having fewer and fewer licensed clinicians, and having Peers help Peers and Family help Family instead, there will be more people being hospitalized. and more people becoming more ill. Our experienced psychologists and clinicians help keep people well and able to cope with their illnesses. As family and friends, we can be an important support, but should not be a substitute for needed professionals.

Thank you for allowing me to express some of my concerns.

12. Santa Clara County has had a great MHSA process. They sent out 10,000 surveys and conducted interviews. They included four threshold languages – Spanish, Chinese, Vietnamese, and Tagalong. A Leadership Committee included members from schools, the police, hospitals, NAMI and other community organizations. They held public reviews in three different areas and then sent their plans to the Mental Health Board.

    As each MHSA component has been released, they've held special meetings to include all the groups already mentioned. They set up a County Housing Advisory Board, had "tuition" to attend CIT Conferences, and set money aside for special ethnic outreach programs. From their MHSA county education funds, they gave NAMI Santa Clara funding for the Provider Course, for a Peer Pals programs and for African American outreach.

13. There are often 200 client members attending these MHSA Stakeholder meetings in OC. Most often only about five family members and about 20 to 30 professionals attend these meetings. More evening meetings need to be held to involve family members. More advance notice of meetings is also needed. An outreach to working family members is beginning this fall with four evening meetings scheduled for November on ***Developing an Orange County MHSA plan for Workforce Education and Training.***
    One of the OC Mental Health Board members emailed me the following and I agree on the "consensus" issue. "In Orange County the stakeholders' process seems to be o.k. in all respects except one. **The use of "consensus" here means "unanimous." I believe agreement by consensus should be more than a majority but less than unanimous. One lone holdout should not be able to thwart the process from moving on."**

14. Ventura County has adhered to priorities set through the stakeholder process . The first QI reports to the MHB subcommittees started yesterday, Nov. 1st with a presentation to the Adult Services Committee and will continue to other subcommittees at their November meetings. It's a bit early to judge, but things seem to be moving as planned and as expected.

15. In Santa Clara County, there are regularly scheduled meetings which are good. Getting sufficient family and client participation in these meetings is difficult. Our NAMI volunteers in both categories are spread quite thin. Not sure if stipends for attending meetings would help, but particularly for clients, they might. We are very glad to have two part-time family coordinators on board with the county now--one focusing on the adult population and the other on children's needs.

16. Please forgive me for what I am about to say your not going to like as well as the State and most Communities!
    At All Stakeholder Meeting where Carol Hood or Other State Officals are there Older Adults are left out and I have Brought and we get OH (Yes !) and the STILL after a year process leave them OUT ! MONEY wise its a SHAME State-wise as well as in the COUNTIES! There isn't a person in this State who isn't going to be one or have a Family member or be one that's a Client or Consumer one day and may need these services and the Medical Model division doesn't know how to serve our population and give Quality od care other to stick them into Locked facilities which we are closing(Thank God So where will Our People GO? I Ask You to get Quality of Care and Dr. Mayberg and Carol Hood and Many Of Us won't be around for every to Advocate and undo what's been done can it be changed then or will people be stuck? As they have been in the past/ so why not fix the problem before it Occurs now that's being Ignored WHICH is our Senior Population/I don't know you but this could be you or you Family member in a couple of years we don't know what could hit any of our families I know they as an Ex- Nurse my Parents never thought I could end up in the system or that I thought my Parents could have Cancer or Depression in their last days and other disorders or that there could be Bi-Polar in our family or disorder or other things until I was Diagnosed and family was afraid to talk about it with stigma .)I know this is the same old stories you've heard Right! Please don't leave out the Older Adult Populations I see it ALL OVER THIS DOCUMENTATION!

17. Not working well. Not as far as I know. Nothing done. I mean, end results. At least not well enough known for me. No reporting, not to my level. And I have issued a formal request to Christina Alejo Garcia. Christina responded

to me right away but didn't have requested info available. Christina, and especially David Weikel, have been super outstanding prompt responses and abundant distributions and support. They are at Aliant University. David is the Executive Director of MHA.

I don't understand the word STAKEHOLDER. I guess it would be a mental health client. Maybe also people who support mental health sufferers. I got more into NAMI this summer, and fall. I certified thru Fresno County Peer to Peer Support training this spring, summer NAMI Peer to Peer Support training, then NAMI Peer to Peer Support Mentor training in Sacramento, then the NAMI Convention in Irvine. I have become interested in MHSA and have attended everything I could about it. I have listened, taken notes, and asked questions. I am also a Recovery International trained leader, and a Toastmaster.
I suggested they report actions and expenditures. Report requests, determination, and reason. Describe, easily understandable, how suggestions, requests, issues can be submitted. That the submitter can see verifiable noting of his item and the history of its handling.
Ricky Miller on the Mental Health Board is a huge resource for focus and motivation.
Counties need Mental Health Courts. Some counties received MHSA funds to create and support. Most didn't. The tall lady who works with Judge Chitick is knowledgeable and has worked a lot on this.

18. Dede, I just want to make a comment. Here is South Lake Tahoe we still do not have good emergency services, a place to hold someone for evaluation, sometimes no beds available to put some one in crisis and especally children without going out of our county. How are they going to do early intervention with out these services. Basic needs still are not being met but they are moving on with new programs

19. Families generally seem to be an afterthought.
Often, meetings are scheduled during the day so working folks can't join or just the retired family members participate – and that's becoming all consuming for us retirees. In our county, there is much more attention paid to consumers' needs. The county just doesn't understand that there are, simplistically, two groups of consumers – those that can advocate for themselves strongly and those that need family members to talk for them since they are too sick. The county listens exclusively to the first group, and that group wants nothing to do with housing such as board and cares; the push is all on recovery and independence and our relatives aren't even on that page.

20. **The transformative process of the plan should include**
Some expectations of results to help reduce serious and persistent mental illness.

Community Collaboration

Local and county to county: I think this issue has to be addressed in a big way to truly achieve the transformation and transparent system we strive for. The issue of confidentiality is a double edged sword. It protects the client (or does it) but it impedes community , family and most of all the client to get the intervention in the time of crisis**." It is this issue that families have been concerned about for years. When behavior is menacing and threatening we must find a way to comfortably address this.**

Critical information sharing faces substantial obstacles:

Elected officials, healthcare providers, law endorcement personnel, and others are not fully informed about when they can share critical information on persons who are likely to be a danger to self or others, and the resulting confusion may chill legitimate information sharing. Virginia Tech Report

21. I believe it is going very well. The department makes an effort to be sure that stakeholders are truly a part of the process. The committees I'm on have a good balance between department employees, contract providers, family members, and consumers. (Tehachapi)

22. In Marin it is very CMHS controlled with appearance of an open process. Service delivery is divided down the middle between county union workers and community contract agencies.

23. Many community members have commented to me that although there were focus groups for the initial process community member input was not considered in the plans that were actualized. This creates an atmosphere of "why bother" " if they're not going to listen to us anyway".
There also seems to be quite a bit of confusion around terms and language. The MHSA documents and notifications create barriers through "technical" and/or specific "bureaucratic speak". For instance, a required MH Board Meeting was announced to present for "public review" the Community Services Implementation Plan. Community members were frustrated and confused that there was a discussion about whether **they could provide input** and also that the "plan" had already been approved in July. It was also frustrating that the comments that were finally allowed were "submitted" with the finalized Plan and had no impact to the Plan being submitted.

24. . We are in the process of putting together the Adult Council which has been in existence only a few months. We have decided to include the whole MH delivery system (Design & Integration) and base it on The Recovery Model starting with the most severe: Crises Services and going all the way down to the least impacting. Along the way we are going to rate them or if we don't offer something we feel we need we'll note that, too. Then we propose to rate Access to Care for all the services. Finally we shall do Outcomes and Oversight.

The Children's System of Care Council has been in existence the longest and they just got a boost when North SD County opened up a 5 day a week Children's Assessment Center. Up to now families and children without proper insurance had to be assessed in Chula Vista. Oceanside is a huge improvement.

We still need more crisis beds in North County having only 11 for 1M people. Crisis beds in the County are always full and it is hard to step patients down from the hospitals if there is no room. They are often stuck in hospitals costing far more than necessary simply because there is no room elsewhere.

Is your local stakeholder process meeting the needs of your ethnic/cultural communities? Please explain.

1. I would say NO. For simplar reasons to the above the meeting are not well attended by many groups and as far as I know only those that speak spanish have a different meeting to attend.

2. Wowie, that was alot of information to think about. I guess I will start with what I know. I have been to a few of the Tulare County MSHA meetings and they seem to have some good CD's and films that they have made for Spanish speaking families. I think there should be some better way of marketing this information to the families that need these services. How are we going to get the information to them? These mental health commercials are great on TV and maybe if they could add a line or two about " different languages available" to local people would be so helpful. Also in my opinion the social workers, therapists, Psychiatrist, Psychologist need to have some type of cultural school so they know what is rude or socially unacceptable for the different Asian, Arabic, Mexican, South American, African and so they can communicate more effectively. This should be done in casual, fun and informative environment for the people giving services. These barriers need to be broken so family members can support the one with the mental illness in the family and trust their service advisor or therapist. As we all know, once there is trust then the information can be gathered by everyone. I hope this answers some of your questions.

3. a. While I can't speak directly for these communities, a "Latino Advisory Committee" was formed consisting of Latino consumers and family members. Members of this committee also participated as members of the "Consumer and Family Advisory Committtee mentioned above. Initially, some members of this committee regularly attended the C/F Advisory Committee but have not recently. I suspect the location and time of the meetings may have something to do with this as some of these folks are recently employed or have changed jobs making attendence more difficult.

   b. In our county, cultural/ethnic translates to Latino and Asian (Hmong) and both of these communities have proven difficult to engage in the MHSA process or in pretty much anything else relating to mental health services. I think that our county mental health department and all of us stakeholders are still searching for effective ways to engage these folks. Approaches to date have had some limited success but this looks like a long term project.

4. I don't believe the stakeholder process is addressing the much needed attention to university campuses because of the reason listed above. My daughter is a junior at a university and the no. of students on campus with mental illness is huge. As we know, this is true throughout our country and solid attention and funding needs to be paid to this.

5. It appears that translators have been available.

6. All ethnicities are represented

7. Yes. I see a great effort for inclusion of many ethnicities that exist in Orange County.

8. The ethnic/cultural communities in <u>our</u> area will not come to a meeting that is a general/vague invitation. The Mental Health Department needs to make a concerted effort to invite **each** group with a written invitation (on an official letterhead) expressing acknowledgement of the value of the group's unique experiences/knowledge about their communities strengths, needs, barriers. When approached with respect, groups will be more likely to respond and be involved in the process. There should never be a focus group with just a few of any group....expressing the needs of a whole community. There are diverse ideas/experiences in all ethnic/cultural groups that need to be expressed.

9. The concerns of different ethnic and cultural communities are well accommodated in that there is a great deal of focus on reaching the various communities and hiring bilingual staff, in the new programs as well as existing ones. One thing I have noticed at meetings, however, is that it is not easy to quickly understand the meeting process and how to provide input when one is not a member of the provider/professional community. While yet another meeting for training might not be the answer, providing some training material online ahead of meetings might be helpful, as might communication with our family coordinators (see above). Such discussion might make it easier for family members and clients to contribute meaningfully.
I am also American Indian and Blackfoot the Black and the Mexican and Asian Populations are always included but Indians and White are now Excluded Yes I did say Whites also. Also the Male Population is underserved!

10. **No. No one has offered me something to read defining organization, procedures, and processes. If such exist I wonder where and how to get. Have I dropped the ball not doing something I needed to. I don't know this. If not available, MHSA has plenty of money to hire qualified planners and documenters to support presenting educating information to subscribers. This need if it exists needs to be filled at/for local and state.**

11. It's trying to meet those needs but seems to be floundering. I haven't seen any effective way to connect when there are a myriad of culture and language obstacles. The intent is certainly there.

12. The committees I work on don't reflect the demographics of our county. However, we are very aware of that and are making efforts to encourage stakeholders from the various cultural communities. It is hard, however, to overcome cultural barriers concerning mental illness.

13. The elephant in the room, the huge, mostly illegal latino population in Marin. At least one rep is invited from the Hispanic, Black and Vietnamese communities. I think Hispanic population is very underrepresented. It is very politically charged and not discussed openly. We are building a new county health campus in the middle of the largest latino neighborhood in Marin.

14. I'm not sure about this. We have a very limited ethnic demographic in Shasta County.

15. Yes. We are definitely making headway. We are treating the Latino population in their various communities, and in their language so treatment becomes more comfortable, as well as more readily available.We have also set up a program for those that have suffered from political violence and torture, and are planning a Chaldean Outpatient Program in East County. We are including services to the deaf and the blind.

    We are setting up a TAY Clubhouse mindful of the fact that young people do better with their peers. We still need more such separated programs linked to other clubhouses or on separate sites.

    We still have a long way to go with permanent housing. It takes so long to set up new housing that we are having the most luck with rental subsidies, vouchers and deposit assistance; at least a greater number are finding a roof over their heads, which is huge.
    Also the new ACT program seems to be working well. We have increased diversity by working In North County with Interfaith Community Services, which has just finished renovating a 6 bedroom joint home project with NAMI. It is the first Fairweather Lodge housing model in CA. and is located in Escondido. In addition, a family member builder and his brother are footing an 18 bed IL project also in Escondido. Although no MHSA funds have gone as yet into these facilities the community is becoming increasingly aware that we desperately need more housing, especially supportive housing and it is inspiring agencies and people to help. .

    Overall I do worry about the continued fragmentation of the system.
    What I really don't want is to end up with a multitude of meaningful programs. They are too difficult to oversee. In addition, if we want to get rid of labels, why are we separating all these programs and labeling them ourselves. We are just as much at fault if not more so as we should know better. The problem should NOT define the person, and it does in the way it is set up.

16. I am truly sorry that I was not able to give praise to this process. Sadly, my county is notorious for a lack of communication. It seems like many times if one is not living and working within the system in Bakersfield it takes many hours of research to find out anything.

    There is a desperate state-wide shortage of affordable, safe housing for the mentally ill. Also, there are almost no county programs to help us with civil and criminal legal matters when we most need it. Most of the legal assistance programs have had funding cuts and have cut services as a result. Also, the programs that exist now know very little about mental illness or the laws that affect us.

    As a client, I can tell you that my fondest wish is to have low-income housing. My town, Tehachapi, with a population of over 20,000 has only 15 housing units available for low-income, non-seniors.

    While I have never had any need for criminal legal help, thank God, I am currently attempting to do my own bankruptcy without legal assistance, because none is available.

I am also being sued in Kern County Superior court for a debt collection, limited civial case. This too, I have had to handle without any legal advise. When I was first served with papers regarding this lawsuit, I spent many hours online and on the phone researching and trying to find someone to help me. My case and circumstances are very typical and demonstrate a very real need in our state mental health system. Almost none of us clients can go through out daily lives without some kind of civil and/or criminal cases against us. We are not able to understand what is happening, what is expected of us, or even how the court system works. We desperately need legal assistance, especially help that has a knowledge and background of mental health laws and how the laws can be used in our favor.

How is the MHSA stakeholder process working at the statewide MHSA stakeholder meetings that are held in your region? What is good/not-so-good/or could be improved?

1. There is time to get those in the population that do not drive to the meeting because they are planned however the meeting are often so big that individuals do not feel that they will achieve anything by going. They believe there voices will nto be heard in that crowd.

2. The concerns I expressed regarding local meetings apply to statewide meetings. The exception is the suicide meeting I attended where everyone seemed to have equal opportunity to speak.

3. Again, locations throughout the year can be held around the population's regions to help the community as a whole be included.

4. Also, more effort is needed to get the word out for these specific meetings.

5. Difficult to get working family and client members to attend as meetings are held in the day time hours . More outreach to family members is needed.

6. The one regional stakeholder meeting I attended in San Francisco so far was worthwhile.

7. The Meetings have been held at different times so the public can be there and at first there was a lot of interest and there is always food! Which helps and the time is good but Interest has gone down. People don't see it moving as fast as it should be its the gov't doing the same old same old and the same old getting the same contracts! Some people are disappointed, to small of Numbers of Clients being Hired.

8. What meetings?

9. Dede is doing a great job keeping us informed.

10. I've only "attended" on stakeholder meeting and it was a conference call. The problem with the statewide meetings is the short notice. Sometimes I don't know there's a meeting until the day of or days later.

11. The meeting for our region was cancelled. This should absolutely be rescheduled. **The underlying question is, is our input less important than other regions??**

12. All the state meetings I have attended for stakeholders I have felt were well run and interested in local input. I do not think there is enough publicity though, particularly in newspapers or TV.

Is this regional/statewide stakeholder process meeting the needs of your ethnic/cultural communities? Please explain.

1. I am not sure our ethnic communities are made aware of the state meetings in our area

2. In 0range County it is inclusive.

3. I believe it is attempting to do that. It is difficult to get the Hispanic community to be involved but they do have some representation. Vietnamese community is represented.

4. It is always important to keep in focus the overarching group to be served by MHSA; i.e. people with serious mental illness in our communities from all cultural and ethnic groups. Because of their illnesses, these folks have common difficulties obtaining services, communicating their needs, and managing to maintain the supports that will help them reach their appropriate levels of recovery. Often this focus appears to be diluted by the details involved with planning for the various different groups.

5. No.

6. Not sure – I've only been to one meeting and outside of Native American groups, I saw no other community represented.

7. I would say no. But how to attract them is not so easy. I do not have the idea that an effort is made to discover who their spokespeople are. I think this is true of most groups.

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